

PATRON: H. R. H. THE DUCHESS OF KENT



THE HAEMOPHILIA SOCIETY

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MINUTES OF THE TWELTH MEETING OF THE EXECUTIVE COMMITTEE OF THE HAEMOPHILIA SOCIETY held on Tuesday 12 April 1983 at 6.30 p.m. at the White Hall Hotel, Montague Street, London WC1.

Those present: The Revd. A.J. Tanner, C. Knight, Mrs. M.I. Britten, K. Milne,
D. Rosenblatt, H.N. Abrahams, Dr. L. Kuttner
In attendance: D.G. Watters

AGENDA

- 83.38 Apologies for absence.
- 83.39 Minutes of the meeting held on 3 March 1983.
- 83.40 Matters arising.
- 83.41 Presentation of draft Annual Report & Accounts.
- 83.42 Seminar Report-back.
- 83.43 Case Committee.
- 83.44 Research Grants Committee.
- 83.45 Acting Honorary Secretary's Report.
- 83.46 Honorary Treasurer's Report.
- 83.47 Groups.
- 83.48 World Federation of Hemophilia.
- 83.49 Co-ordinator's Report.
- 83.50 Any other business.
- 83.51 Date & Place of next meeting.

83.38 APOLOGIES FOR ABSENCE were received from Mr. Prothero and Mr. Johnstone.

83.39 MINUTES of the meeting held on 3 March 1983: The following corrections to the minutes were noted:

83.30(b) GRO-D

83.32 Notable donations... GRO-D £210 (In memory of his mother

GRO-D).

83.34 ADD "... redundant equipment, for our help to India.

83.35(b) Seventh line should read £1.55 per tile.

83.36 The spelling of Chairman was corrected.

Having noted these amendments the minutes were unanimously approved as a correct record of proceedings at the meeting.

83.40 MATTERS ARISING

- (a) Recent resignations: The Chairman reported on recent correspondence received from Mr. Polton.
- (b) Oxford Lottery: Mr. Rosenblatt reported no further news from G & S Co. Ltd's solicitors.
- (c) Incorporation: The Co-ordinator reported on the convening of an Extraordinary General Meeting to amend the present Rules and Regulations and obtain the necessary approvals to proceed to Incorporation. The formal notice would be circulated later in the week, along with a covering letter from the Chairman, giving the required seven days notice.
- (d) One-day mini-Seminars: Valuable discussion took place on this subject and details were referred back to the Seminar Sub-Committee, augmented by Mr. Milne, for further planning.
- (e) WFH Edition of The Bulletin: Mr. Knight reported that Mr. Milne would assume immediate responsibility for the preparation of this publication.
- (f) WFH Congress: The Co-ordinator reported that all registrations and reservations had now been made and that WFH would pay 50% of his costs since he will be taking part in a session. Discussion also took place concerning the Poster Presentation "Educational Needs" - the Co-ordinator to obtain elucidation from WFH.
- (g) DHSS Sect. 64 & EEC Social Fund: Nothing to report.

83.41 PRESENTATION of DRAFT ANNUAL REPORT & AUDITED ACCOUNTS:

Both documents were discussed in detail and various minor amendments made to the Annual Report which will be presented to the Council and AGM.

83.42 SEMINAR REPORT-BACK: Mr. Knight reported that there had been much enthusiastic feed-back following the Seminar and that the Sub-Committee had held one initial meeting to begin planning the 1984 Seminar.

83.43 CASE COMMITTEE: The Co-ordinator reported that the Case Committee had met earlier in the afternoon and wished to make the following recommendations to the Executive Committee:-

- (i) A grant of £50 to assist a seriously handicapped member with his mobility.
- (ii) A grant of £50 to assist a member with holiday costs, on the recommendation of her Centre Director.
- (iii) A grant of £40 to assist a family with holiday costs, on the recommendation of their Centre Director.
- (iv) Grants of £20, £30, £30, £20 to meet individual cases of need on the recommendation of a social worker.
- (v) A grant of £50 to meet a case of hardship, again on the recommendation of a social worker.
- (vi) No grant to assist with the education of the parent of a haemophilic child.

Mr. Abrahams proposed and Mr. Milne seconded the approval of these grants which were agreed unanimously.

83.44 RESEARCH GRANTS COMMITTEE: The Co-ordinator reported on the deliberations of the Research Grants Committee which had met earlier in the day.

- (a) St. Thomas' Hospital, London: An application in the sum of £11,235 in respect of work related to acquired immune deficiency syndrome (AIDS). It was felt that this application should be referred to the Medical Advisory Panel.
- (b) Oxford Haemophilia Centre: Dr. Rizza had submitted a modified application on behalf of Mr. Winship. The Executive Committee agreed unanimously that this application should not succeed.
- (c) Middlesex Hospital Medical School: An application for work connected with inhibitors in the sum of £3,000 in the first year and £1,500 in the second year. The Committee recommend that the application be referred to the Medical Advisory Panel.
- (d) Bradford Royal Infirmary: Dr. Parapia applied for a grant in the sum of £3,000 per year for two years to fund a part-time MLSO to help to establish a new haemophilia clinic. The Committee recommend that the application succeed in the sum of £3,000 for the first year as a pump-priming exercise.
- (e) St. James's University Hospital, Leeds: Dr. Swinburne applied for an extension of a grant, originally granted in 1980, for the purpose of taking the project to completion in April 1984 (in the sum of £1,750). Dr. Swinburne indicated a possibility of extending the work further into 1984 in the sum of £3,500. The Committee recommend a grant of £1,750 but that no further application connected with the work could be considered.

83.45 ACTING HONORARY SECRETARY'S REPORT: There was no report.

83.46 HONORARY TREASURER'S REPORT:

BALANCES:	Current Account	2,516.97
	Ordinary Deposit Account	14,688.54
	Fixed Deposit Account	100,000.00
	Research Fund to date:	226,429.61

Notable donations: Norfolk & Norwich Group £500 Research; GRO-A £51 General; British Rail Southern Region £25 Research; GRO-A £50 and GRO-D £150 In memory of GRO-A; Trustees Cecil Rosen Foundation £25 General; GRO-A £80 (Deed) General; From estate of GRO-A GRO-A £1,686.07 General; Colleagues of the late GRO-A £100 Research; Jersey Group £200 General; Cambridge & District £1,000 Research; N.E. Group £500 Research £100 General; Lewisham £300 Research £200 General; Ladywood (Birmingham) £300 General £200 Research; Sheffield £800 Research; South Wales £500 General; Bristol & S.W. £400 General - overseas work; Landrover UK Ltd. £104.99 Research; Merseyside £802.59 Research; Sussex £400 Research; Man of the People £2,590 Research; Gt. Ormond St. £300 Research £100 General; Prudential Ass. £175 (Deed) General; GRO-A £100 Research.

- 83.47 GROUPS: The Co-ordinator reported that he had attended the AGM of the Lewisham Group and that **GRO-A** had attended the AGM of the North East Group and Great Ormond Street Group. It was noted that the G.O.S. Group had been unable to elect a Committee and consequently would report to the next meeting of the Council.
GRO-A would also attend the AGM of the Oxford Group on Sunday 17 April 1983.
- 83.48 WORLD FEDERATION OF HEMOPHILIA: Mr. Milne reported on correspondence received from **GRO-D** regarding **GRO-D**'s difficulties in travelling to the Stockholm Congress. Following discussion it was agreed that the Co-ordinator should ascertain from **GRO-D** his exact position and also contact the Bristol & South West Group to ascertain their attitude to the use of the £400 donated by them at the March meeting of the Council to assist in **GRO-D**'s transportation costs. The Executive Committee remained clear that the £1,000 already agreed should not be used for this purpose.
- 83.49 CO-ORDINATOR'S REPORT: There was no report.
- 83.50 ANY OTHER BUSINESS: The Chairman expressed his thanks to the members of the Executive Committee for their help and support throughout the year. The Committee in turn extended their thanks to the Chairman for guiding them through what had been a difficult year.
- 83.51 DATE & PLACE OF NEXT MEETING: Thursday 12 May 1983 at the White Hall Hotel, Montague Street, London WC1.

GRO-C

12 May 1983